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Chapter 10

Conceptualising Privacy in Relation to Medical Research Values

Deryck Beyleveld

Introduction

Many medical researchers are hostile towards laws that protect privacy. For example, in November 2000 the *Health Service Journal* reported on a campaign by cancer epidemiologists led by Professor Peto (henceforth, 'the Peto campaign'), that called for all medical research to be exempted from the UK Data Protection Act 1998 and for the common law on confidentiality to be relaxed.¹ In particular, the epidemiologists claimed that the need to obtain consent was impracticable and led to poor research results, which meant that more people were dying than need be the case.

This campaign suggests a particular conception of the relationship between protection of privacy (and other fundamental rights and freedoms implicated in data protection/the protection of confidentiality) and the values that guide (or should guide) medical research, which I will designate 'the conflict model' of the relationship between privacy and medical research values, coupled with a 'narrow' conception of the right to privacy, according to which the only legitimate privacy interest that persons have in the use made of sensitive personal data relating to them is in protection of their personal identities. Such a 'narrow' conception of privacy, which implies that the right to privacy is not engaged in the use of personal data once it has been rendered anonymous, has received some support from the Court of Appeal of England and Wales.² However, I shall argue that the jurisprudence surrounding Article 8.1 of the European Convention on Human Rights (ECHR) consistently propounds a broad conception of this right, according to which it protects a very wide range of interests. Indeed, under this 'broad' conception, any use made of sensitive personal data engages Article 8.1 of the ECHR unless explicit consent has been given by the person to whom it relates. Without this consent, *any* use made of sensitive personal data will be a breach of Article 8 ECHR, *unless* a justification for

1 'Cancer Experts Call for Action on GMC's Confidentiality Rules', 2 November 2000 *Health Service Journal*, 4.

2 *R v. Department of Health, Ex Parte Source Informatics Ltd.* [1999] 4 All ER 185 in the High Court, [2000] 1 All ER 786 in the Court of Appeal of England and Wales. See note 3.

this is available under Article 8.2 ECHR. Given the place of the ECHR in relation to UK domestic law, to EC law, and the relationship between EC law and UK domestic law, legally, the broad conception must be adopted.

I will also argue that the broad conception of privacy implies a complex set of relationships between privacy and medical research values, in which these values, while certainly capable of coming into conflict, can also systematically support each other, which suggests a different model, which I will call the 'co-operative model'. I will argue that this conception is also implied by standard public interest reasons (ignored by the Court of Appeal in *Source Informatics*³) for considering data relating to a person's health given to health professionals to be confidential. In addition, there are good ethical reasons for preferring the co-operative model.

Finally, I will make some suggestions as to how conflicts between privacy and medical research values (which can still arise within the co-operative model) are to be assessed.

Narrow Conception: The Source Informatics Case

In *R v. Department of Health Ex Parte Source Informatics Ltd.*,⁴ Source Informatics Ltd., a database company seeking to obtain information about GPs prescribing habits from pharmacists, which it hoped to sell to pharmaceutical companies for the purposes of direct marketing of GPs, applied for declaratory relief against advice given to pharmacists and GPs by the Department of Health in a letter to Health Authorities. The letter advised that GPs and pharmacists who participated in such schemes without the consent of patients would be acting in breach of confidence even if the information was disclosed to database companies like Source Informatics Ltd. in anonymous form, because patients give the information for their treatment not for the purposes of these schemes. In the High Court, Latham J declared the Department of Health's advice to be lawful. However, this judgment was overturned on appeal (in which the General Medical Council, the Medical Research Council, the Association of British Pharmaceutical Industries and the National Pharmaceutical Association all intervened on the side of Source Informatics Ltd.). The Court of Appeal's reasoning (Simon Brown LJ giving the leading judgment, which was supported without comment by Aldous LJ and Schiemann LJ) was essentially that the basis of the duty of confidence in the use of information given by patients to health professionals for their treatment lies in equity, with the consequence that the scope of the duty rests on nothing more and nothing less than whether there can be further use or disclosure of the data without unfair treatment of the patient.

³ *Supra cit.*

⁴ *R v. Department of Health, Ex Parte Source Informatics Ltd. supra cit.* For full commentaries see Beyleveld, D. and Histed, E., 'Anonymisation is not Exoneration', 4 (1999) *Medical Law International*, 69-80 and Beyleveld, D. and Histed, E., 'Betrayal of Confidence in the Court of Appeal', 4 (2000) *Medical Law International*, 277-311.

According the Court, unfair treatment is treatment contrary to the legitimate interests of the patient, and in:

a case like the present which involves personal confidences ... [t]he concern of the law ... is to protect the confider's personal privacy. That and that alone is the right at issue in this case.⁵

In relation to this, the Court held that concealment of the confider's personal identity in any further disclosures or uses of the confided information is sufficient to secure protection of the confider's personal privacy.⁶ Thus, since pharmacists were only handing over anonymised (indeed, aggregated) data, '[t]he patient's privacy will have been safeguarded, not invaded. The pharmacists' duty of confidence will not have been breached'.⁷

While the Court did not go quite so far as to declare that once personal information is rendered anonymous it can, under no circumstances whatsoever, continue to attract a duty of confidence,⁸ the Court nonetheless adopted a very narrow conception of privacy. In particular, the Court rejected the idea that the use of the information without the consent of the patient necessarily involves a breach of confidence, because a breach of confidence is not, in essence, use of information contrary to the purposes for which it was confided; the test is rather whether or not further use satisfies the confidant's 'own conscience, no more and no less'.⁹ On this, it matters only what a reasonable confidant may do. Thus, the Court is required to ask:

[O]n the facts of this case: would a reasonable pharmacist's conscience be troubled by the proposed use to be made of the patients' prescriptions? Would he think that by entering Source's scheme he was breaking his customers' confidence, making unconscientious use of the information they provide?¹⁰

And the Court gave clear indication that not only would it not consider unconsented use to be unfair (and by the same token, a breach of privacy/confidentiality), but that it would even be prepared to countenance use against the patient's explicit objection, for in the Court's view, there is a need to find a solution to:

[s]uch problems as the well-recognised reluctance of certain people to accept the views of those in authority as to just what is or is not good for them, and, let us postulate, the occasional patient who expressly purports to refuse permission for his prescription form to be used for any purpose save only the dispensing of the prescribed drug.¹¹

5 [2000] 1 All ER 786, at p. 797.

6 *Id.*

7 *Id.*

8 *Ibid.*, at p. 792.

9 *Ibid.*, at p. 796.

10 *Id.*

11 *Ibid.*, at n. 800.

While the case concerned confidentiality, not data protection, it should be noted that the Court was drawn to declare that processing of the information by the GPs and pharmacists would not fall under the Data Protection Directive¹² because Recital 26 thereof states that the principles of data protection shall not apply to data rendered anonymous in such a way that the data subject is no longer identifiable directly or indirectly by anyone. When it was argued on behalf of the Department of Health that the Directive, by specifying anything done 'upon' personal data as processing of it, including deletion and destruction of it, renders anonymisation of it a process performed upon personal data,¹³ to which (according the Recital 26) the principles of protection must apply, the Court held that this only has a bearing on cases where erasure 'could impair the patient's own health requirements'.¹⁴ Bearing in mind that Article 1.1 of the Directive has it that the object of the Directive is to protect fundamental rights and freedoms, in particular, privacy, in the processing of personal data, this is questionable unless a very narrow conception of privacy is employed.

Broad Conception: Jurisprudence of the ECHR

A different conception of privacy is to be found in the jurisprudence of the European Court of Human Rights and the (now defunct) Commission on Human Rights of the Council of Europe.

According to Professor Jacques Velu, the right to respect for private life under Article 8.1 of the European Convention on Human Rights protects the individual against:

1. attacks on his physical or mental integrity or his moral or intellectual freedom;
2. attacks on his honour and reputation and similar torts;
3. the use of his name, identity or likeness;
4. being spied upon, watched or harassed;
5. the disclosure of information protected by the duty of professional secrecy.¹⁵

Similar statements are routinely made by the European Court of Human Rights in its judgments.¹⁶

So broad is the conception of this jurisprudence that, as L.G. Loucaides has rightly concluded, case law under the European Convention on Human Rights:

12 Directive 95/46/EC.

13 See Article 2(c).

14 [2000] 1 All ER 786, at p. 799.

15 'The European Convention on Human Rights and the Right to Respect for Private Life, the Home and Communications', in Robertson, A.H. (ed), *Privacy and Human Rights*, Manchester, Manchester University Press, 1973, 12-128, at p. 92.

16 See, e.g., *P.G. and J.H. v. the United Kingdom* (44787/98 [2001] ECHR 546 (25 September 2001)). para 56 and the further references given there.

has expounded and upheld the protection of privacy to such a degree that, for all practical purposes, the right of privacy has become a functional equivalent of a right of personality, potentially embracing all those constituent parts of the personality of the individual that are not expressly safeguarded by the European Convention.¹⁷

Furthermore, that this jurisprudence is contrary to the 'narrow' conception has been explicitly recognised by the Commission of the Council of Europe, according to which, while:

[f]or numerous Anglo-Saxon and French authors the right to respect for 'private life' is ... the right to live as far as one wishes, protected from publicity ... the right to respect for private life does not end there [but includes also the right to] ... the development and fulfilment of one's own personality.¹⁸

From this it should come as no surprise that, according to the European Court of Human Rights, failure to obtain explicit consent for the use of sensitive personal information automatically engages Article 8.1 of the ECHR (hence the right to private life, and privacy), meaning that any unconsented use of such information is a violation of the right to privacy, *unless* justified within the terms of Article 8.2.¹⁹

The Narrow Conception and the Conflict Model of the Relationship

The conflict model of the relationship between privacy and medical research values is characterised by the idea that privacy conflicts with medical research and does not in any way support it. However, this idea can lead to two opposed views because neither the relative value to be attached to medical research values and privacy, nor a specific view of what values medical research seeks to protect, are part of the conflict model *per se*. However, those medical researchers who see privacy as essentially a hindrance to medical research to be removed are apt to claim (or at least strongly imply) that the values that medical research seeks to promote are exclusively values like human health and human life. If so, it is reasonably inferred that the values that medical research seeks to promote are always more important than privacy. Ergo, if there is any conflict between privacy and medical research, then privacy must give way. At the extreme, particularly if the narrow conception of privacy is coupled with the conflict model, this can result in the view that patients have a duty to engage in medical research to the extent that their consent is not required unless the research itself is life threatening or involves serious risk of physical harm. On the other hand,

17 'Personality and Privacy Under the European Convention on Human Rights', *British Yearbook of International Law*, LXI, 1990, 175-197, at p. 196.

18 Application No. 6825/74 DR5, 87.

19 See, e.g., the European Court of Human Rights in, e.g., *Z. v. Finland* [1997] ECHR 10 (25 February 1997), paras 96-97, *M.S. v. Sweden* (1997) 28 EHRR 313, para 34 (in relation to medical data) and in *Peck v. the United Kingdom* [2003] ECHR 44 (28 January 2003), paras 78-80 (in relation to other sensitive personal data).

opposed to this, if the conflict model is coupled with the broad conception of privacy that sees it as a personality right, it can be held that the right to privacy is, in effect, the right to autonomy, even the right to dignity, in which case (because human dignity is often thought of as the basis of human rights),²⁰ this can yield the view that medical research can never be undertaken without consent.²¹ However, because the conflict model is normally associated with the narrow concept of privacy and, as I will argue in the next section, there are tensions, even a contradiction between the conflict model and any conception of privacy that is at least as broad as that operated by the European Court of Human Rights, I will not consider this coupling further.

When the narrow conception of privacy is coupled with the conflict model, there are at least two other variables that are capable of influencing the effect of this coupling on the importance to be attached to privacy in any conflict with medical research values. The first of these is the view taken of the basis of the values at stake. The second, which might not be entirely independent of the first, is the view taken of the kind of exercise that must be performed to assess the weight that the conflicting values have. In relation to the first of these, those who adopt the narrow conception-conflict model coupling frequently (though not necessarily) tend to regard the right to privacy as grounded in the value to be given to a person's personal wishes (as a personal interest), whereas they tend to see the values of medical research to be grounded in the public interest (what is good for people in general). In relation to the second of these, they tend to see the balance to be assessed in a utilitarian manner, which is to say by the idea that the overarching value to be served is the promotion of the wishes/the good of the greatest possible number. This combination inevitably has the consequence that restrictions on privacy (serving to promote the general good) are to be broadly defined, whereas privacy restrictions on medical research (serving only individual interests) are to be narrowly defined. This has the further effect that the onus is on those whose privacy is threatened by medical research to establish their case, should the possibility that they might have a case be recognised at all.

The Broad Conception and the Co-operative Model of the Relationship

The central idea that guides a co-operative model of the relationship between privacy and medical research interests is that while the two sets of values are capable of coming into conflict, they are also capable of supporting each other. Essentially, the idea is that protecting privacy can facilitate medical research interests and, conversely, medical research can enhance privacy interests.

20 See the opening of the Preamble to the Universal Declaration of Human Rights proclaimed by the General Assembly of the United Nations on 10 December 1948, which Declaration the European Convention on Human Rights aims to give partial effect to.

21 Such a broad view of the right to privacy must not be confused with the broad conception operated by the European Court of Human Rights. The right to privacy under Article 8 ECHR cannot be a right to autonomy as such and certainly not the right to human dignity as the basis of human rights. Were this the case, the ECHR could not provide derogations from privacy in its Article 8.2, which it does.

The idea that protecting privacy can support medical research is not novel. For example, it has long been recognised that one of the reasons for the law to protect privacy²² and confidentiality²³ is that it is in the public interest to do so. That those who become ill seek proper medical treatment is in the public interest, because for them not to do so means that the risk that they might pass diseases on to others is increased, and they are more likely to be absent from work, both of which are contrary to the public interest. It is also in the public interest that patients are candid with the information they provide to those who are to treat them. Inadequate or false information will, at the very least, not facilitate adequate treatment. However, if they are to seek treatment and be candid with their doctors, patients must trust them to respect their privacy and confidences (to the extent of not making any unconsented use of the information that the patients would find objectionable, as well as not disclosing information in a way that might embarrass or harm them).

While this thinking is most familiar in the context of medical treatment, it may, however, also be applied to medical research. This is for at least two reasons. First, medical researchers are very often clinicians, so to facilitate trust in clinicians is to facilitate trust in medical researchers (and conversely, to damage trust in clinicians is to damage trust in medical researchers and *vice versa*). Secondly, even when medical researchers are not clinicians, the information they disclose in medical research is equally sensitive and, by the same reasoning applicable to information disclosed for medical treatment, must be handled with respect for privacy and confidentiality.

In relation to this, it should be noted that supporting privacy in medical research does not merely make it more likely that persons will agree to be subjects in medical research. Trust in medical researchers makes it very much more likely that the information gained will be accurate and reliable, which is essential for research to meet its objectives.

Another way in which protecting privacy might support medical research is suggested by the thinking behind the EC Data Protection Directive. As I have already mentioned, the aim of Directive 95/46/EC is to protect fundamental rights and freedoms, in particular privacy in the processing of personal data. However, as Recitals 7 and 8 of the Directive make clear, at least part of the thinking behind this is that such protection is necessary for it to be possible for there to be transfer of data across the European Union. This is because Member States, being party to the European Convention on Human Rights and other international human rights instruments, are committed to protection of fundamental rights and freedoms, and many of them have this protection enshrined in their constitutions. Thus, if personal data does not receive the necessary rights protection, Member States will not permit personal data to be transferred to countries that do not provide the necessary protection needed for the internal market in personal data to be possible. However, given such a context and given the need for multi-national medical trials if such

22 See, e.g., the European Court of Human Rights in *Z v. Finland* (22009/93) [1997] ECHR 10 (25 February 1997), para 85.

23 See, e.g., *W v. Egdeell* [1990] Ch 359, at p. 419 and p. 422.

research is to be most effective, protection of privacy, etc., is necessary for such medical research.

The idea that medical research can support privacy is, perhaps, less obvious. However, this idea is inherently plausible under the broad conception of privacy. Under this conception, the values that privacy protects include rights to bodily integrity and rights to control over persons' personal lives. Medical research, by, at least in principle, facilitating alternative and better treatments and a better quality of life for those who become ill or simply age, has the potential to give people more control over their lives by providing them with more and better therapeutic options.

One of the consequences of a broad conception of privacy is that privacy does not merely protect one value, but several. So, not only is privacy capable of conflicting with other non-privacy interests, but some privacy interests are capable of conflicting with each other. Furthermore, such a conflict need not be interpersonal, it can also be intrapersonal. Bearing in mind that medical researchers, patients and research subjects are not inherently different populations, all have interests in medical research and privacy. Consequently, the complex interactions that exist between privacy and medical research mean that conflicts between privacy and medical research values may often be best described as conflicts between different privacy values or as between different medical research values.

Justifying the Co-operative Model

If the broad conception of privacy outlined implies a co-operative model, then justifying this conception will justify this co-operative model. Since this conception is that of the European Court of Human Rights, this can be done by justifying following this Court's jurisprudence. In the UK, at least, a strong case can be made for this from a legal point of view.

First, Section 3 of the Human Rights Act 1998 requires all legislation and indeed, all common law (see s 6) to be interpreted so as to be consistent with the rights granted by, *inter alia*, Articles 2-12 and 14 of the ECHR, unless prevented from doing so by primary legislation, if it is at all possible to do so. Regarding this latter proviso, the UK Courts have been prepared to strain interpretative licence to the limit to avoid declarations of incompatibility with the ECHR.²⁴ Furthermore, s 2.1(a) of the Act requires the UK courts to take favourable account of the views of the European Court of Human Rights.²⁵ While this is weaker than a requirement to comply with the views of the Strasbourg Court, not to do so is an open invitation for litigation at the Court, with the almost inevitable result that judgment will be against the UK. While the UK Government has recently made noises about ignoring such judgments, such action has not yet been taken.

24 See, e.g., *R v. A* [2001] 3 WLR 1546 and *R v. Lambert* [2001] 3 WLR 206.

25 The *Source Informatics* judgment was delivered shortly before the Human Rights Act 1998 came into force.

Secondly, the use of personal health data in all research falls within the scope of Directive 95/46/EC on data protection, and clinical trials on medicinal products for human use fall within the scope of Directives 2001/20/EC ('Clinical Trials Directive') and Directive 2005/28/EC ('Good Clinical Practice Directive') (both of which require Directive 95/46/EC to be observed). Article 6(2)EU requires the EU to respect the rights guaranteed by the ECHR as general principles of EC law (and Article 288 of the EC Treaty requires the European Court of Justice (ECJ) to apply general principles common to the Member States, which has led the ECJ to go so far as to declare that any EC legislation that does not comply with such principles is null and void).²⁶ Of course, the EU is not as such party to the ECHR and the European Court of Human Rights is not a court of the EU, so its judgments can only have persuasive, not legally binding, effect. However, for the ECJ to rule contrary to such judgments is to invite constitutional crisis in the Member States because of the doctrine of supremacy of EC law and the fact that many Member States are bound by their constitutions to respect the views of the European Court of Human Rights.

Apart from strictly legal reasons to adopt the broad conception/the co-operative model, there are also ethical reasons. The co-operative model of the relationship between privacy and medical research values sits naturally with a co-operative model of the relationship between medical researchers and medical subjects. In this latter model, research subjects must be viewed as partners in a communal enterprise in which there is mutual (and not merely reciprocal) respect for the rights and fundamental interests of all parties. In effect, researchers must view research subjects not as information crops to be harvested for the common good or their own purposes, but as partners whose purposes are to be respected as though they were the researcher's own. In Kantian terms, research subjects are to be treated as ends in themselves, with their consent *always* being required for invasions of their rights unless it is necessary to override this for the more important rights of others. But, crucially, researchers must not merely not interfere with the rights of research subjects, but must positively assist them to enjoy these rights. This is especially important where research subjects are concerned, and even more so when they are patients. This is because patients and research participants are in a vulnerable position in relation to unconsented use of their personal data – for example, they might not know of various uses at all; even when they do, the damage might already have been done; and, in such cases, their opportunities for redress will be slim (they are not usually in a good position, due to lack of resources or knowledge, to complain, let alone take legal action, and must further risk conflict with those upon whom they rely for their treatment when they are ill or weak). Consequently, unless the research culture is regulated (and better still guided) by the goal of respecting research subjects as ends in themselves, the rights and interests of research subjects will be endemically threatened by medical research.

Finally, there are pragmatic reasons for adopting the broad conception/co-operative model. A research culture that is based first and foremost on consent encourages trust

26 See, e.g., *The Second Nold Case (Case-4 73)* [1974] E.C.R. 507.

and enables data to be kept in a form that is of most use for research, as it can be richer, is more likely to be accurate and can be corrected. It also, generally, carries the fewest legal risks and is likely to be associated with the best clinical outcomes.²⁷ Such reasons, of course, are those that lie behind the idea that protection of privacy is in the public interest²⁸ and, indeed, in the public interest in medical research.

The Co-operative Model and Assessing Conflicts of Interest

Even within the co-operative model conflicts of interest are possible. The right to privacy is not absolute, and can be overridden by other values. This is expressly recognised by Article 8.2 of the ECHR, according to which no public authority²⁹ may interfere with the right granted by Article 8.1:

except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

This provides the general framework for considering conflicts between privacy and research values. As Article 8.2 has consistently been applied, research values can only be permitted (by public authorities, including, most particularly, the State) to override the right to privacy if to do so is necessary for the protection of one of the values expressly stated in Article 8.2, the derogation is proportionate (i.e., no greater than necessary), and the derogation is provided for by law. In principle, subject to these conditions, to the extent that medical research can be held to be for the protection of the rights and freedoms of others/be for the protection of health, derogation is available for this purpose. However, it should not be thought that this

27 See Beyleveld, D. and Brownsword, R., 'Ethics Committees: Public Interest, Private Interest, and the Ethics of Partnership'. in Lebeer, G. (ed), *Ethical Function in Hospital Ethics Committees*, Amsterdam, IOS Press, 2002, 135-149.

28 It is worth noting that the Court of Appeal, unlike the High Court, in *Source Informatics*, ignored this consideration altogether.

29 While the ECHR is directly enforceable only against public authorities at the European Court of Human Rights (i.e., is only vertically effective), it does not follow that the rights granted by the ECHR are not rights held against individuals (i.e., not horizontally applicable). The idea that the right of Article 8.1 may be derogated from for the rights of others implies that the rights of the ECHR are held against individuals (i.e., that they are horizontally applicable). So, it is arguable that effect can only be given to them domestically if they are horizontally effective in domestic law (see, further, Beyleveld, D. and Pattinson, S., 'Horizontal Applicability and Horizontal Effect', October (2002) *Law Quarterly Review*, 623-644). However, even if this is controversial, the ECHR will, in any event, be horizontally effective in domestic law when used to interpret domestic law that provides actions against individuals.

provides the opening for a *carte blanche* exemption for research from the need to protect privacy.

In the first case, this is because it is questionable to what extent medical research may be said to be for the protection of health or represent a right or fundamental freedom of others. The basic reason for this is that privacy (like all the human rights and freedoms of the ECHR) is a fundamental value, and it is in the nature of fundamental values that they can only be set aside to protect other (indeed, more important) fundamental values. It might be objected to this that, in that case, reference to anything other than the rights and freedoms of others is the only purpose necessary. However, this does not actually follow. It is surely the case that the other purposes mentioned are all things that are necessary to protect very important rights and freedoms of others: breakdowns in public safety, health, national security, etc. can (indeed, often do) all threaten life and the necessary means to these (such as adequate food, clothing, shelter, etc.). With this in mind, I suggest that specific reference to the rights and freedoms of others is reference to case specific conflicts between rights, whereas the other derogatory purposes are purposes that, in a standing way, are rights threatening. Thus, the first problem for a *carte blanche* exemption for medical research is that its purposes might not be purposes that constitute the protection of a human right or that are expressions of a fundamental freedom.

But there is also another problem. This is that the condition of proportionality is not merely applicable to the degree of rights violation. It also involves the idea that the overriding purpose must be more important than the value to be overridden in case of conflict. This raises the question of how to assess the relative value of different rights and fundamental freedoms in the ECHR. While it is arguable that the rights protected by those Articles of the ECHR that are subject to very restricted derogation outweigh those (mainly Articles 8, 9, 10, 11 and 12) that are subject to wide derogatory provision, this does not help with conflicts between the right of an individual of Article 8 and the rights of others of Articles 8, 9, 10, 11 and 12), and it still leaves the rights that are more important without a clear rationale for ordering.

However, it is surely irrational to grant a right to something yet not to grant a right to the necessary means to enjoy this right. So, if there are conditions that are necessary for the exercise or having of all rights, then a right must be granted to these no matter what rights are granted. Since, in principle, rights could be granted to any actions, such conditions must be necessary for all actions. I suggest, therefore, that the difference between a fundamental right and freedom and other rights and freedoms is that the latter are things the absence of which is detrimental to the having of any rights or their exercise (and, hence, detrimental to any actions).

Alan Gewirth calls such conditions 'generic features of action'.³⁰ These are ordered in two ways. First, things that are needful to even attempt to act (interference hinders an ability to act at all) ('basic needs': such as life, mental equilibrium, the general ability to exercise choices, and the necessary means to these, such as food,

30 Gewirth, A., *Reason and Morality*, Chicago, University of Chicago Press, 1978, pp. 48-63

clothing and shelter) are distinguished from things needful for general chances of success in achieving purposes through one's actions (subdivided into things needful to maintain abilities to act – 'non-subtractive needs', such as accurate information; and things that generically enhance one's abilities to act – 'additive needs', such as further education). Second, within and between these categories, importance is to be assessed by the degree to which the generic features are needful for action and successful action (in relation to which Gewirth suggests that the psychological theory of Maslow³¹ might be helpful).

Gewirth makes much larger claims for this scheme of rights: *viz.*, that agents deny that they are agents if they fail to recognise and act according to it. However, while I believe that Gewirth is right about this,³² it is not necessary to accept this to see the use (even the necessity) of deploying such a scheme given a recognition of human rights).³³

From this perspective, the Peto campaign³⁴ is based on mistaken or misguided thinking on a number of counts. First, the campaign seeks a *carte blanche* exemption for medical research. This ignores the fact that privacy is a human right and that not all medical research purposes engage human rights and fundamental freedoms: it is too broad a church for that. Since this is so, there can be no avoiding the need to make purpose by purpose assessments of the *possibility* of an exemption.

Second, even if a fundamental value is engaged by the research, it must be necessary to override privacy. In other words, the research goals must *require* privacy to be overridden. However, provided that consent is obtained, there is no conflict; the research may be carried out without interference with the right to privacy. On this front, the Peto campaign claimed that consent was impracticable. However, while this might be the case where data has been collected in the past without consent, it is difficult to see how this can be the case when data is being collected prospectively. It is often said that more harm is caused by putting clinicians to the inconvenience of getting consent than by not obtaining consent. However, this judgment is usually made from the perspective of ignoring the public interest reasons for protecting privacy and is not often accompanied by any consideration of how consent might be obtained without placing too great a burden on clinicians. Additionally, the Peto campaign claimed that it is necessary to obtain data from 100 per cent of the population for epidemiological studies on cancer, so the fact that some patients or research subjects might refuse consent damages the research irremediably. This is, however, extremely dubious if generalised to all medical research. Indeed, if the claim is sound it would argue for all medical research to be carried out without

31 Maslow, A.F., *Motivation and Personality*, New York, Harper and Brothers, 1954, pp. 80ff.

32 See Beyleveld, D., *The Dialectical Necessity of Morality*, Chicago, University of Chicago Press, 1991.

33 For further elaboration, see Beyleveld, D. and Brownsword, R., *Human Dignity in Bioethics and Biolaw*, Oxford, Oxford University Press 2001, pp. 79-86.

34 See note 1. *supra*.

consent. It is also very dubious in relation to cancer epidemiology since the idea of a 100 per cent sample can only really mean 100 per cent of the human race. The fact of the matter is that research results can be of varying degrees of value: they are not either perfect or of no value at all, and degrees of compromise are necessary and possible to get the optimal balance of protection. Any other way of thinking ignores that breaches of privacy must be proportionate.

Of course, the Peto campaign will have been bolstered by the decision of the Court of Appeal of England and Wales in *Source Informatics*. However, the Court's idea that privacy is not engaged unless breach of privacy would cause specific extrinsic harms (which would render processing of the information unfair) simply does not accord with the view of the European Court of Human Rights that the right to privacy is always engaged by the use of health data without explicit consent. It is clear that one of the motivations behind the Court's judgment was to do away with case by case judgments of whether or not confidentiality (and by the same token, privacy) may be overridden in the public interest (or by countervailing values).³⁵ However, the Court seemed to be oblivious of the fact that it was merely replacing the need for case by case assessment of this by case by case assessments of fairness. But, most seriously, the Court's thinking simply does not conform with the thinking required by recognition of the fact that privacy is a human right and the jurisprudence of the European Court of Human Rights on this matter.

Conclusion

Prima facie, the idea that privacy in medical research protects merely against disclosure of sensitive or confidential personal information and the extrinsic harms that this can cause is attractive to medical researchers, because it suggests that protecting against such disclosures is all that is necessary for such information to be used in research. However, I have argued that such a position is not legally tenable, because the interfaces between UK domestic law, EC law and the European Convention on Human Rights, require a broad concept of privacy to be deployed. While this is likely to prompt many researchers to call for the law to be changed, it should now be clear that this is short-sighted. There are both ethical and pragmatic reasons for adopting a broad conception of privacy. These are not merely negative (e.g. appreciation that consent fosters an atmosphere of trust which is necessary for medical research to flourish), they are also positive (e.g., a consent culture actively encourages a willingness for people to engage in medical research and improves the quality of results). Wholehearted adoption of the broad conception, however, requires the deployment of a co-operative model rather than a conflict model of the relationship between privacy values and medical research values.

35 [2000] 1 All ER 796, at p. 800.